

**Written Submission on the Joint Standing
Committee on the National Disability
Insurance Scheme Inquiry into NDIS Planning**



Submitted To:
Joint Standing Committee on the National
Disability Insurance Scheme

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About Queenslanders with Disability Network (QDN)

[Queenslanders with Disability Network](#) (QDN) is an organisation of, for, and with people with disability. The organisation's motto is "nothing about us without us". QDN operates a state-wide network of members who provide information, feedback and views from a consumer perspective to inform systemic policy feedback and advocacy to Government and peak bodies.

QDN has over 2000 members and supporters across Queensland who provide QDN with the perspectives of people with disability. This submission is informed by the lived experience of our members.

Introduction

QDN welcomes the opportunity to make a submission to the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) Inquiry into NDIS Planning. The NDIS is a critical investment in the supports and needs of people with disability to live their day to day life in their communities, based upon principles of choice and control. NDIS participants want to access quality, affordable and integrated supports across mainstream, community and specialist services. QDN believes it is critical to get the NDIS planning process right for people so that participants can access the supports they need to be achieve active social and economic participation in their communities.

QDN's response to the NDIS planning Inquiry is informed by:

- Our 2,000 strong membership and support base
- Our 20 [Local Support Groups](#) across the state
- QDN work and engagement with over 21,300 people with disability and their families in delivering the following projects and initiatives:

[NDIS Peer to Peer Advocacy](#)

[Getting on the NDIS Grid](#)

[Ready to go NDIS Participant Readiness project](#)

QDN's response will present a brief summary of the issues in relation to planning and then respond to the 10 areas the inquiry is seeking further information on, particularly highlighting the critical need for people with disability to have access to formal independent advocacy and support in the NDIS planning process.

Brief summary of the issues in relation to NDIS Planning

QDN has been working alongside people with disability and families over the past 5 years to ensure those eligible for the NDIS have the correct information and 'hands-on' support to make access into the NDIS. Many Queenslanders with disability who are eligible for the scheme need additional support, funding to cover assessment costs and advocacy to get the paperwork and evidence together in a streamlined way that meets National Disability Insurance Agency (NDIA) requirements.

Additionally, QDN and our allies have successfully delivered innovative 'hands-on' projects to marginalised and vulnerable people with disability as outlined above, supporting them to access the scheme and get an NDIS plan. Trust, connections and relationships are crucial to getting buy-in and good outcomes for this group.

There needs to be continued investment by Government in organisations with such expertise and established relationships, to continue to undertake this work if Queensland is to increase the number of new participants coming into the scheme and secure the additional 30,000 plus new participants as agreed upon as part of Queensland's bi-lateral agreement with the Commonwealth. This pre-access work delivers benefits to participants in the planning phases also, ensuring participants understand what their functional impacts are, what day to day support needs they have, and what funded supports the NDIS deems are reasonable and necessary.

QDN members are experiencing blockages and continued challenges with securing, activating and implementing their NDIS plans. People report frustrations in getting sufficient funding to cover the supports they require, including transport and supports coordination. Members also report significant time delays in getting plans approved and progressed, especially in relation to assistive technology and home modifications.

The role and importance of peer support, self-advocacy, independent individual and systems advocacy is critical to delivering positive outcomes for people with disability, and ensuring the systems supporting them work effectively, including the NDIS.

QDN sees a need to build the market and to increase participants' capacity to utilise plan management and self-management approaches, so that people have real choice and control with their services, especially in the rural and remote parts of the state where there are 'thin markets'. Strategies and investment need to be in place to build people's capacity around plan management and self-management and to build options where providers are thin on the ground.

The experience, expertise and qualifications of planners

“Some planners have backgrounds and experience in disability, while others have nothing at all. Some do not have enough empathy”, feedback from a QDN member.

QDN members report mixed feedback about the experience, expertise and qualifications of planners. Some members have had positive experiences saying they are “very happy” and have been “extremely fortunate as the planner was reasonably knowledgeable”. While another person reported: “the planner was pretty hopeless, he seemed good at the meeting but didn’t give me any information about where to get support and didn’t return my call for two weeks”.

A consistent theme regarding planners is that the onus is on the individual to express their needs well: “if you are able to express your needs, you will do well. If you can’t do this you may miss out on the essential supports you need. It all comes down to how well the person can tell their stories and explain their needs. You need to be able to express what your goals are and what supports you need to achieve your goals”.

Another QDN member responded: “The NDIS is incredibly complicated. If you are very organised, it can work very well. But if you’re not organised, or have difficulties organising yourself, it can be difficult. If the process was a little bit simpler it would be better”.

Further feedback from QDN members indicates that some people’s plans are being done by their services and have limited or no input from individuals, and that some people are disappointed by their plans because they feel the planners did not listen to them.

These member reflections highlight the need for people with disability and their families and supporters to have access to advocacy and peer support to navigate the NDIS planning process. As reported by a QDN member in regional Queensland: “I found it very easy due to peer support”. This was backed up by another member who said: “I found the planners pretty good, providing the participants were able to relay the information in a way planners would accept. It is better to have a person in the room with you”.

QDN’s experience of assisting people to navigate the NDIS indicates that Planners need additional training to understand the diverse needs of people with disability. For example, if a person has previously had negative experiences with systems or authority and has difficulty articulating what they need, they may not be able to clearly give information about their needs and link them to goals and therefore not get their basic needs met in their plan. Feedback from QDN’s peer support workers also identifies that some people may give inaccurate information about the level of their support needs, “playing them down”, as generally, people with disability want to portray a positive, highly competent image of

themselves to someone they perceive to be in a level of authority, perhaps resulting in the person not getting the funded support they need to have a good quality of life.

In our work with individuals, QDN observes that generally planners do not ask open-ended questions to elicit information from individuals. This can result in vital information about a person's support needs being missed. Hence, the presence of an independent support person can help to draw these issues out further. Also QDN feedback indicates there are instances where the Local Area Coordinator (LAC) has led the planning process and critical information about the individual getting lost when they feed the information up to the NDIS planners who sign-off on the plans.

Another key theme that has emerged from QDN members about the experience of Planners is the language they use. Many people with disability, particularly those with intellectual or cognitive disability, report feelings of confusion regarding the language used by planners in planning meetings, many saying they need to ask simpler questions and use simple language. The NDIS planning process needs to be accessible for all individuals accessing the scheme, and it is not appropriate for people to become disengaged as a result of an inaccessible process.

Many QDN members believe the NDIS needs to have more planners with experience of disability, including people with disability themselves, so they have increased empathy of the lived experience of disability and knowledge of the specific support needs of people with disability.

The ability of planners to understand and address complex needs

“Complex needs often refers to a variety of conditions and circumstances of the person, whereas the NDIS has a focus on the individual's primary condition”, QDN Project Officer.

QDN has experience of working with people with complex needs through our Getting on the NDIS Grid project where we engaged with 3937 people with disability. This project worked with people under 65 who experienced additional challenges engaging with the National Disability Insurance Scheme (NDIS), and the organisations who work with them to:

- find out about the NDIS,
- see if the NDIS is for them,
- think about how the NDIS can help them meet their needs, and
- know how to apply to the NDIS

The project worked with people with disability who are:

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- transient, living in supported accommodation, living in caravan parks and/or experiencing housing challenges;
- homeless, or at risk of homelessness;
- exiting the child safety, criminal justice and juvenile justice systems; and
- from lesbian, gay, bisexual, transsexual, queer, intersex and asexual communities (LGBTQIA).

In our work with individuals QDN found there are many barriers for individuals in achieving 'access met' status. Two of the biggest barriers being gathering relevant supporting evidence and Access Request Forms not completed appropriately.

Some people, in particular people with cognitive impairment and psychosocial disability, do not identify with disability and are used to the further disadvantage they experience, and believe they are not eligible for the NDIS.

Literacy skill levels can make it difficult to understand access request requirements and participants will often give up on the process. Communication and information provision needs to be easy to understand and participants supported to continue with the access request process.

Furthermore, the project found people residing in caravan parks, or who are homeless or at risk of homelessness often:

- do not have any informal or formal support in their life
- do not have a relationship with a General Practitioner or Allied Health Professional
- do not have any current documentation or evidence supporting their functional impact
- do not have the capacity or capabilities to request documentation from previous service support e.g. assessments, health records
- do not have the income to support payment for assessment or supporting evidence
- do not identify with having a disability and therefore believe they are not eligible for the NDIS
- experience further disadvantage and identify these as a priority (often this is survival)
- experience psychosocial disability or cognitive impairment, and/or substance misuse
- want to be an NDIS participant however need to address further disadvantages (e.g. substance misuse) prior to making an Access Request

In 2018-2019 QDN worked with 1435 individuals in our Peer to Peer Advocacy Project. The purpose of the project was to support people with disability around the NDIS including access, pre-planning and planning. More specifically the target group for the project were people with disability who were new participants to the scheme including people who are hard to reach and experience a range of complexities and interfaces, often with multiple service

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systems across homelessness, child safety, juvenile justice, domestic and family violence, health, criminal justice systems. The project provided individuals with pre-access, access, pre-planning and planning meeting supports.

Through this project, QDN found individuals with complex support needs have multiple connecting issues in their lives that span disability, health, behavioural and social issues. This can sometimes conflict with the NDIS approach of focussing on an individual's primary condition.

Complex needs can be disability-related and life related, for example, additional to a disability there are other factors including the incidence of domestic violence, the impact of homelessness and leaving prison. These issues, often in combination with one another, require planners and people working alongside individuals in the planning process to access services and support from a wide variety of government systems and community organisations. 'Complexity' is often seen as a product of individual life situations and the failure of support structures to respond appropriately over time.

People with complex support needs are more likely to require intensive and coordinated support for a longer duration than other people with disability. Planning is an important element in supporting people with complex support needs effectively.

In QDN's experience of supporting individuals, if a person does not have a support person, assisting them with preparing for the planning meeting, and also during the planning process, complex needs are at risk of not being identified. QDN has observed that at times the planner does not ask the right questions about the other impacts and systems in the person's life and consequently, will not illicit this information. Therefore, questions from the planner need to be more purposefully structured to understand the complexities of people's support needs.

Feedback from QDN members concur that people with complex needs need a support person to be with them to express their needs in the planning process. Many people accessing the NDIS may not have family members or friends to assist them. QDN believes this support needs to be provided, wherever possible, by an independent person, not a service provider connected to the individual as this poses a conflict of interest. It is also important for planning conversations to give the adequate time a person needs to gather a holistic picture of the person's life. Having skilled, knowledgeable, professional planners with the patience to work effectively with people to understand their needs is really important. QDN members confirm that people with complex needs are very used to being in crisis mode that "coordinating all the services required just hasn't happened. A person can be kicked out of a service as the service didn't understand their complex behaviour".

The ongoing training and professional development of planners

“Planners need specific training in [the impact of] each disability and the ability to relate to people with disability”, QDN Local Group Convenor.

QDN believes that any training delivered to planners needs to be co-designed and delivered by people with disability. Co-design is central to QDN’s practice in delivery of projects and initiatives for people with disability. Good policy and good decision making happens when the people who use the services or products are part of their planning, design, delivery and evaluation from the beginning. It is also critical that decision makers invest in their capacity to listen to, hear and respond to the input from people with disability to deliver good governance and implement a plan that will achieve an all abilities Queensland.

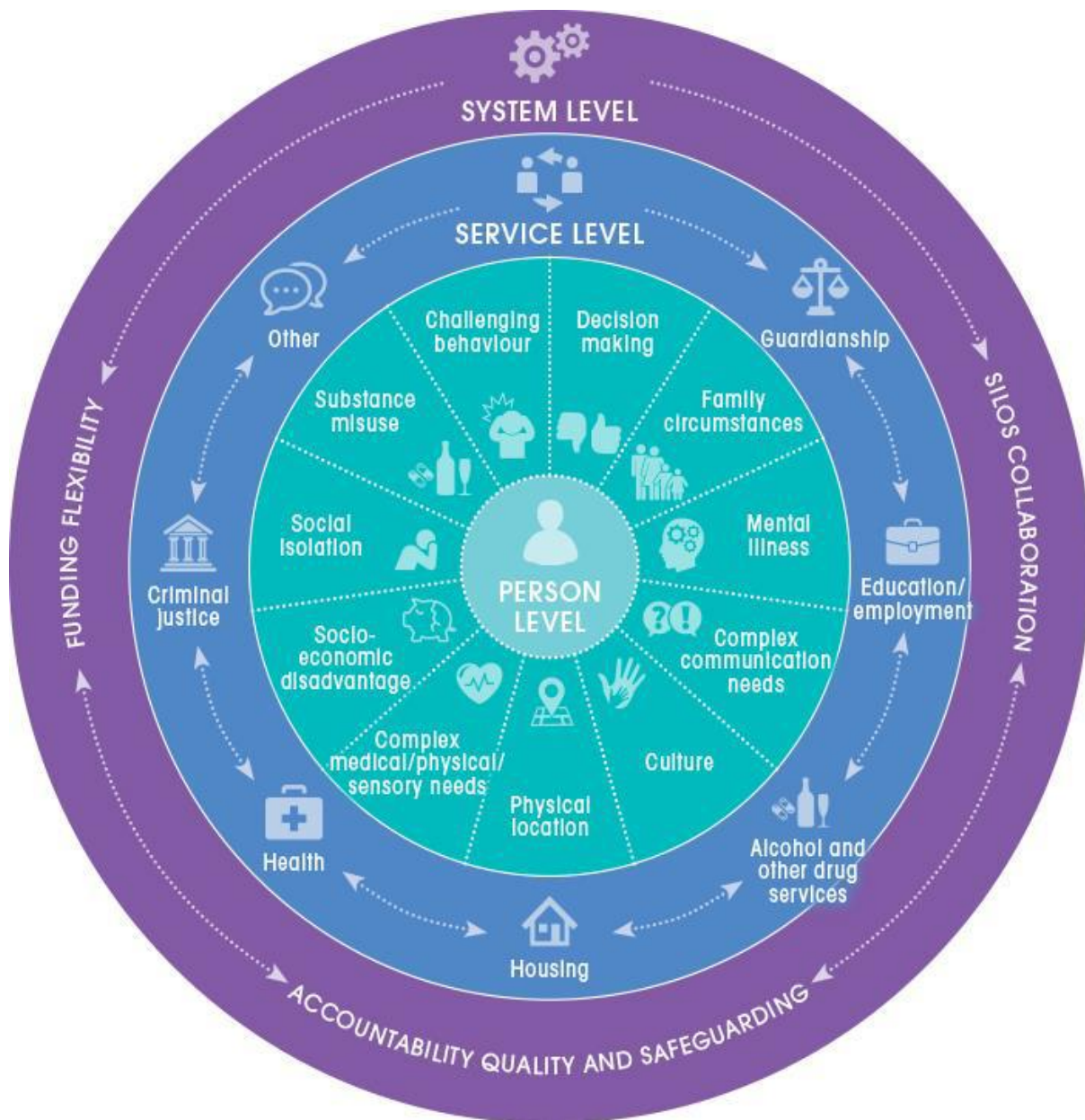
Overwhelmingly, feedback from QDN members indicates that training for planners needs to have a focus on the knowledge of the functional impact of each disability type and the ability to relate to people with disability in order to achieve the best possible outcomes for people with disability in the planning process.

As part of QDN’s NDIS Peer-to-Peer Advocacy Project funded by Queensland’s Department of Communities, Disability Services and Seniors, QDN undertook work to develop a guide for staff working on the project supporting people with complex needs to be able to identify complexity of need with the individuals they were supporting to access the NDIS.¹

QDN believes there needs to be training for planners on developing a holistic picture of people with disability and the overlapping issues, services and systems that impact their lives in order to fully understand their needs. People with disability often face intersecting barriers to their full inclusion in life. The diagram below identifies the many different factors impacting on people with disability². QDN believes it is important for all planners to have this holistic understanding:

¹ Peer to Peer Advocacy – Complex Support Needs Resource, QDN, 2018

² The Complex Support Needs Planning Toolkit has been developed by the University of New South Wales: Collings, S., Dew, A., & Dowse, L., UNSW (2015). BEING A PLANNER WITH A PERSON WITH DISABILITY AND COMPLEX SUPPORT NEEDS: PLANNING RESOURCE KIT. UNSW: Sydney. The Planning Resource Kit can be downloaded at: <http://unsworks.unsw.edu.au/fapi/datastream/unsworks:38962/binaf8273d1-eff4-4199-b95b-a99ee48e2fd2?view=true>



Using this approach requires planners to have professional, analytical skills, to look beyond a stated script of questions and have a high level of skill and insight to ask specific questions relevant to the person and identify individual needs.

QDN asserts there will still be a role for formal advocates in the planning process as QDN are aware that even people who were well prepared and highly skilled and competent experienced challenges and admitted to feeling overwhelmed by the planning process.

Further suggestions from QDN members on relevant training for planners include:

- How they engage with persons with disability to understand what their daily life is like

- specific communication skills on how to deal with people who are stressed, problem solving skills
- skills on how to communicate with people who have communication barriers because of a disability or belonging to a culturally or linguistically diverse background. Working effectively with interpreters should be mandatory training for all planners.

The overall number of planners relative to the demand for plans

“Waiting times seem to be getting longer between the access approved and planning meeting stages”, QDN Peer Advocate.

QDN is aware of some inconsistencies around this and is also aware of delays in getting access approved, particularly for people who are new to the system. QDN is concerned that individuals who do not have advocates may probably just leave it and potentially fall through the system and miss out on accessing vital supports.

QDN is aware of a community perception that the NDIS is always going to have a backlog as there are so many people trying to get through. QDN regularly encourages members and other people with disability to stick with the process as there are far fewer options now to get disability support through the state government.

QDN is aware each State and Territory has different impacts upon demand for plans. Queensland is different, for instance, because the bilateral agreement states 50 percent of NDIS participants are to come from existing clients of the state and the other 50 percent are to be people new to disability services. Recently the transitional period has been extended to June 2020, however, this highlights that planning for scheme implementation in Queensland needs to have a different approach and consideration, with considerable emphasis and strategies developed for finding the people, many of whom have been previously disenfranchised from the service system and supporting them to join the Scheme.

Participant involvement in planning processes and the efficacy of introducing draft plans

“I had people sticking up for me in the meeting and this made a difference and helped me to feel included in the meeting”, QDN member.

QDN supports the full involvement of people with disability in the planning process. QDN has been involved in projects supporting people with high and complex needs to learn about

the NDIS and be involved in the planning process to the full extent of their abilities. This requires a high level of skill and knowledge of how the person communicates and it takes time to get to know the person and understand their communication styles and their skills and interests.

Generally QDN members felt they were involved in the planning process and for some this was enhanced through independent pre-planning support and the presence of advocates in the planning meeting: “I had a peer advocate and assistance with pre-planning. This was very helpful”. QDN members highlight that assistance to think about quality goals is essential in the pre-planning phase to ensure they are able to access the supports they need and achieve social and economic participation.

QDN supports the idea of participants being able to review draft plans and believes this could potentially reduce the number of plan reviews. QDN believes if this could occur without delays to the overall process it would be very useful and enable people to feel more involved and in control of the planning process. QDN believes that people who have support in pre-planning, then have greater capacity to be involved in the planning meeting. QDN Project Officers report regularly having to direct the planner back to the person so they are included.

QDN members also highlight the importance of having assistance to gather the supporting documentation so it is ready for the planning meeting. This greatly enhances people’s capacity to participate in the planning process.

It is important to consider these measures in the infancy period of the scheme, as people in Queensland are still going through their initial planning process, through to others who are now on their third plan. Change takes time, and QDN believes that it would be better to provide investment into people with disability at the beginning to assist them to understand, navigate and be supported well to build capacity, rather than when things do not work at the other end with plan reviews. Feedback and experience demonstrates that when people get the support they need to be well-prepared, this pays off in plans that meet needs, and they do not need reviews and follow up.

QDN members also concur that seeing a draft plan would be “really helpful before it is approved. This is important to ensuring it is reflective of the planning conversation and will cut down on the amount of reviews”. There was some concern from members that this may take longer for plans to get approved.

QDN members also note that there needs to be a link between the stated goal and the resources allocated to achieve that goal in NDIS plans. Members have experienced confusion regarding the language used in plans and understanding how resources have been allocated in plans and what each section of the plan means. This suggests people need additional

support to understand their plans and budgets so they can effectively implement their plans. Members also report they need more support around “how” to achieve goals in their plans, also highlighting the need for assistance to activate plans and the importance of funding for supports coordination in plans.

The incidence, severity and impact of plan gaps; the reassessment process, including the incidence and impact of funding changes

“The main reason for plan gaps is because individuals have not received adequate support in the pre-planning phase and have therefore been unable to adequately identify and articulate their support needs”, QDN Project Officer.

QDN believes there are a number of contributing factors to plan gaps, which include:

- skills, knowledge and capacity of planners
- inadequate support to individuals during the pre-planning phase;
- inadequate investment into the capacity building of people with disability and their families for plan implementation and plan activation;
- inadequate delivery of skilled and nationally consistent supports coordination

Queensland’s bilateral agreement includes 50% of people who have previously received supports, as well as 50% new participants who have never had any interaction with a disability service system before. QDN has observed when individuals have not received adequate support in the pre-planning phase, the result has been that they have been unable to adequately articulate their support needs in the planning meeting, leading to plan gaps. QDN is also aware there are still major gaps in plan implementation as people are confused about where to go to get access to the supports they need. This is especially pertinent in areas of thin markets and regional/remote communities as there are no services available for participants to access. However, this has also been seen in metropolitan city areas. Significant underutilisation of plans has resulted in people receiving fewer supports once their plans are reviewed. It is important to note that this is not necessarily indicative of the level of need but rather gaps in information on available services or gaps entirely of services. As the NDIS is an emerging market QDN believes there should be leniency on cuts to plan budgets, particularly when it can be proven there are extenuating circumstances preventing a person accessing the supports they need.

QDN is also concerned and is aware of incidences where there has been confusion by participants about language used by the Local Area Coordinator (LAC). QDN is aware that LACs use the term ‘pre-planning’ to describe an actual planning meeting. This can be confusing and

misleading for participants. QDN is aware of one situation where the advocate was not present at the meeting as the participant and her family thought it was only a pre-planning meeting, not the actual meeting where they would be discussing what reasonable and necessary supports would be part of the individual's plan. As a result the participant was not given support coordination, support around finding and keeping a job and some Assistive Technology (AT) was missing. When they questioned the outcome, they were told by the LAC that if they put in for a review the participant may get less. QDN believes this is the result of misinformation and interaction between NDIS and partners, and confusing language.

Some QDN members confirm positive outcomes for their plans, and they attribute this to having support in their planning meeting. Members have also given feedback that it takes a long time to hear progress of reviews and expressed disappointment that the NDIS does not check in to see how things are going. Many people with disability do not have access to informal supports and are isolated in their communities.

One QDN member confirmed that as a result of their plan review, transport funding has gone from periodic payment to part of their core funding. With this change there is no limit to what participants can claim for transport if you have enough funds in core supports. QDN is concerned about the capacity for this to eat into people's core supports and for there to be a shortfall in funding for essential daily living supports.

The review process and means to streamline it; the incidence of appeals to the Administrative Appeals Tribunal (AAT) and possible measures to reduce the number

"People have had difficulties negotiating the appeals process and getting adequate supports", QDN Local Group Convenor.

QDN believes if people received adequate support in the pre-planning phase and had access to formal independent support to attend planning meetings, the need and incidence of plan reviews proceeding to the AAT would decrease.

QDN is aware of the interplay between government systems and what the NDIS provides. For example, people who are deaf and people with vision impairment have to go through additional hoops to justify why they need upgraded equipment to live safely, get a job, and attend to their daily responsibilities. QDN believes the main reason this occurs is because of a breakdown in communication between systems and government departments and programs. QDN is also aware that participants in this situation are also dependent on a planner being receptive to their story. If people are unable to articulate this well, they may experience extensive delays and further disadvantage.

QDN members have experience in initiating reviews due to change of circumstances and many confirm that the need of advocacy in the appeals process is essential. In Queensland funding for NDIS Appeals went to advocacy agencies who were already underfunded and struggling to meet the demand for advocacy on other critical issues facing people with disability and their supporters. This has resulted in lengthy delays for some people in getting the support they need to access the appeals process, and significant unmet need for demand for services to support appeals and reviews. This is despite agencies being funded specifically for this purpose.

The circumstances in which plans could be automatically rolled-over

“If participants are happy with their plans then yes, this could be considered”, QDN member.

QDN gives in principle support to plans being automatically rolled over on the proviso there is no change to the participant’s circumstances and their needs in the next year could be met with the same level of funding. There should always be capacity for participants and their supporters to trigger a plan review and people triggering a review on a plan that has been rolled over should have the review considered in a timely manner.

The circumstances in which longer plans could be introduced

“This would be a good idea if you are happy with it”, QDN member.

QDN acknowledges that for many people the planning process is stressful and the annual process of review can be arduous. Some QDN members have already been put on 24 month plans as a result of their review and report they are happy with this. Therefore, QDN agrees in principle with this idea on the proviso that if a person’s circumstances do change, the process and adjusting of the plan are not complicated and can happen in a timely manner.

QDN member response to this idea was mixed with some saying that it is a good idea as some people take longer to get supports in place and therefore need more time to spend funding. Others felt that this should be an option used with caution as people’s circumstances change from year to year.

Some QDN members felt new assistive technology (AT) requests should not trigger a new plan: “This creates a lot of work for the NDIA and service providers and stress for participants”. Another member suggested: “Maybe there could be an annual AT review, with 2 year plans”.

The adequacy of the planning process for rural and regional participants

“I have the funding but finding a service is complicated, particularly in smaller towns”, QDN member in a regional town.

QDN believes more advocacy is needed for people in regional and remote communities. Technology is also an issue through lack of internet connection in these communities. This is a major issue for participants as funding is managed through the Participant Portal. There is also a lack of services and therefore people in regional/remote communities do not have real choice and control as there are limited or no options.

Members have also expressed the inadequacy of transport funding in regional and remote locations where distances are greater and accessible transport services are not available.

Members have also raised issues with getting plans implemented because of a lack of service providers and therapists in regional and remote locations. Some members spoke of the reality of having to get all your services from the one provider and how it's a different NDIS for people in rural and remote communities because of a lack of choice and control. One member spoke of a negative culture in some towns with service providers saying: “if you don't like it, find another service”, or you have to get all your services from this provider.

People with disability from Aboriginal and Torres Strait Islander communities need targeted approaches that are ‘in community’ and this may look quite different to the individualised nature of the NDIS³.

QDN members have given feedback that getting people to assist with plan access, development and implementation was especially difficult. Issues include access to general practitioners and allied health professionals to support access requests and the need for advocacy and peer support to facilitate pre-planning options. QDN believes people also need capacity building regarding plan management and self-management to allow for broader flexibility of providers, given the thin markets.

³ See, for example, a case study where an elder of the Gimuy Walubara Yidinij people, asked an architect to work with him, on the conceptual design for a facility for Indigenous people with acquired brain injury. The concepts of family and community were central to this design: [file:///qdn-svr/Users\\$/KSwift/Downloads/3385-6515-1-SM.pdf](file:///qdn-svr/Users$/KSwift/Downloads/3385-6515-1-SM.pdf)

Any other related matters

QDN asserts that every new plan should have a component of support coordination attached to it as lack of support at the implementation phase is a major reason why plans are not fully implemented and used. QDN believes that as the NDIS is a new scheme, people need more education and support around navigating the services they need. QDN believes some people may need ongoing supports coordination as this is a recurrent need in an emerging market and people need support to deal with changes in the NDIS policy landscape, especially given the requirement in the Queensland bilateral agreement for 50% new participants who have no prior understanding of disability culture, services and the broader system. These individuals need assistance to navigate so they can successfully activate their plan in a timely manner.

QDN members highlight there also needs to be more opportunities for people to achieve employment goals under the NDIS. Currently members report the NDIS is mainly linking people to pre-existing Disability Employment Services (DES). Generally, people with disability want access to a menu of more flexible employment supports that they self-manage as part of their NDIS supports. This is beyond what traditional DES currently provides.

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